

## Port Allegany Asbestos Health Program: a Community Response to a Public Health Problem

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### Synopsis .....

*The Port Allegany Asbestos Health Program (PAAHP) is a unique, community-run program that resulted from the successful cooperative efforts of a labor union, a corporation, community health care providers,*

*and a medical school. PAAHP's goal is to develop a permanent community health organization that will use the most advanced existing knowledge to mitigate the adverse health effects anticipated as a result of the use of amosite asbestos in a Port Allegany, Pa. factory. All 1,188 persons employed by the factory during the years 1964-72 and the 3,000-4,000 persons in household contact with them are eligible for the program.*

*PAAHP's major services are intensive medical surveillance, smoking cessation assistance, health education for participants, and continuing education for area physicians about asbestos-related diseases. One of the program's policies is not to disturb the usual patterns of medical care. If further testing or treatment is needed, patients are referred to their usual personal physicians. PAAHP does not provide ordinary medical care or medical insurance.*

*Across the nation, the number of workers estimated to have been exposed to asbestos is more than 20 million, and their household contacts are estimated to be about three to four times that number. Adverse health effects resulting from asbestos exposure include elevated risk of lung cancer, mesothelioma, gastrointestinal tumors, and asbestosis. The problem requires the development of public health solutions. PAAHP has demonstrated the feasibility of a community-based model as one useful approach.*

NUMEROUS STUDIES HAVE DOCUMENTED serious health risks—mainly cancer—that result from asbestos exposure (1-5). It has been estimated that at least 20 million residents of the United States may face these risks as a result of past exposures to asbestos (6).

An important unresolved problem is to determine how to diminish or avert asbestos-related disease among those exposed to asbestos. Although less effective than we might wish, interventions now available can lessen the impact of asbestos exposure. Smoking cessation can decrease deaths from cancer of the lung (7), and perhaps of the buccal cavity, pharynx, larynx, and esophagus, as well as from asbestosis. A simple oral examination leading to early detection of neoplastic changes can diminish deaths from cancer of the mouth, tongue, lip, and pharynx. Screening of stools for occult blood can detect colorectal cancers at an early stage (8). Attentive care of intercurrent infections and skillful general pulmonary care can extend the life of those with chronic respiratory

impairments such as asbestosis. Use of influenza and Pneumovax vaccines are effective adjuncts. While data are not conclusive, it is possible that intensive surveillance with sputum cytology and chest X-ray of groups at high risk of lung cancer may reduce deaths from this disease (9). We may look forward to even more effective approaches.

The problem is not entirely, then, a lack of effective measures. Rather, the challenge is how to organize, finance, and deliver the necessary services. The paucity of literature on these questions reflects the meager efforts to date.

A factory in Port Allegany, Pa., has manufactured glass products continuously since 1937. During 1964-72, an amosite asbestos product was also made. A unique, community-run preventive medicine program, the Port Allegany Asbestos Health Program (PAAHP), attempts to use existing means of medical intervention to diminish the impact of asbestos related disease among

some 4,500 persons who were potentially exposed to asbestos. Those eligible for PAAHP services include all persons employed during the years 1964–72 as well as their household contacts during that period. PAAHP resulted from the joint efforts of a labor union, a corporation, community physicians and hospitals, the ministry, a medical school, and community leaders. The program may be useful as a model for communities faced with similar health problems.

## Asbestos Health Effects

The major asbestos-associated causes of death are lung cancer; mesothelioma (pleural and peritoneal); cancers of the gastrointestinal tract, larynx, oropharynx, and kidney; and asbestosis (1). Among persons who install insulation, a well-studied group routinely exposed to asbestos, a four- to five-fold increase in deaths from lung cancer was observed, accounting for 21 percent of all deaths (1). Mesothelioma, an exceedingly rare tumor in the general population, accounted for an added 8 percent of all deaths; asbestosis, 7 percent; and gastrointestinal cancers, 4 percent, a doubling of expected cases (1).

Elapsed time since first exposure to asbestos has been shown to be critical to the risk of asbestos-related disease (1). As a general rule, few asbestos-related deaths occur before 20 years elapse after first exposure. After 20 years, such deaths become more and more numerous, peaking at around 35 years from first exposure. This latent period allows intervention before advanced disease appears.

Risk has been shown to extend to the families of asbestos workers (10,11), presumably as a result of asbestos brought home by workers on their clothes, boots, respirators, and hair. In one study, approximately one-third of 679 household contacts surveyed had radiographic abnormalities characteristic of asbestosis (12). Among persons dying 20 or more years after the first household exposure, mesothelioma accounted for approximately 1 percent of deaths.

Cigarette smoking is a critical factor in determining the severity of health risks consequent to asbestos exposure. Almost all deaths of lung cancer among insulators occurred among current cigarette smokers and former smokers (7). In addition, cigarette smoking appears to be a factor in deaths from cancer of the buccal cavity, pharynx, larynx, and esophagus among insulators, but not in those from mesothelioma, kidney cancer, stomach cancer, or colorectal cancer (7). Most persons with asbestosis who die of respiratory failure also have lungs damaged by cigarette smoking (7).

Asbestos exposure has occurred in a wide variety of industries. Although there is little mining or milling of asbestos in the United States, the mineral has been incorporated into more than 3,000 diverse products. These

include pipe insulation, welding blankets, asbestos cement, cigarette filters, flooring and roofing materials, specialized plastics, textiles, shingles, brake linings, clutch facings, and gaskets. Perhaps the most numerous exposures have occurred among those in shipbuilding and repair; in the construction trades; in chemical facilities, refineries, utilities and powerhouses; and in automobile maintenance (6,13).

Bureau of Labor Statistics figures indicate that more than 27 million people were exposed to asbestos in the United States during the years 1940–79 (6). Of these, more than 20 million were estimated to be alive at the start of the 1980s. These figures are conservative because they exclude household contacts of workers, who may be three or four times as numerous as the workers.

What is known concerning dose-response relationships has led to estimates that 8,200 persons die from asbestos exposure annually in the United States and that almost 10,000 will die annually by 1990 (6). Excess deaths from exposure before 1980 will continue to be significant until about 2030.

Asbestos-related deaths may not be evident constantly because most resemble natural deaths. Lung or stomach cancer in an asbestos-exposed former shipyard worker who is now a clerk is not much different from lung or stomach cancer in a life-long accountant. Detailed and difficult epidemiologic study has been necessary to distinguish asbestos effects on health from natural morbidity and mortality.

Finally, it must be remembered that thousands of people are newly exposed to asbestos every year. Because of the long latency of asbestos-related disease, these current exposures make it likely that the public health problems of asbestos will continue well into the 21st century.

## Previous Approaches

It might be assumed that a public health problem of this magnitude would be attacked with the same vigor as poliomyelitis or insect-borne disease. Unfortunately, this has not been the case. Although there has been important progress in limiting the number and intensity of new exposures to asbestos, few attempts have been made to help the millions of people already exposed.

A few companies have established medical surveillance programs for exposed employees, but eligibility has been defined to exclude most former employees and all but a few current employees, those most heavily exposed. These efforts have usually lacked the confidence of current employees, have been constrained by legal risks to the companies involved, and have usually failed to involve community physicians, thus ensuring that medical attention to the problem would be fragmented. For instance, company physicians in some sur-

veillance programs did not inform workers (or their physicians) that they had asbestosis, apparently because of the compensation claims expected. Without this knowledge, workers could not protect themselves by taking actions such as giving up smoking, nor were their personal physicians alerted to the need for early and aggressive evaluation of chest symptoms that might subsequently arise in these patients.

The largest union-sponsored effort has been mounted by the International Association of Heat and Frost Insulators and Asbestos Workers, a relatively small union (approximately 20,000 members) of skilled tradesmen. Union efforts to notify and educate workers about the hazards of asbestos have been highly effective. However, the complex job of interacting with the health care provider community to ensure medical surveillance, proper followup of findings, and smoking cessation assistance has not been done. This failure is probably because of the logistical problem of the membership's being spread over hundreds of communities across the nation.

Even well-informed exposed workers would be unlikely to obtain the required preventive services individually. It is difficult to locate health care providers who are knowledgeable about asbestos-related diseases. Few medical insurance policies provide coverage for preventive surveillance of "healthy" people, even people at extraordinary risk of disease. Nor do they cover smoking cessation programs, influenza vaccine, and health education. Similarly, worker's compensation insurance does not pay for tests that prevent occupational disease or detect it in the early stages.

In 1978, the U.S. Department of Health, Education, and Welfare, under Secretary Joseph Califano, began a massive attempt to notify workers of asbestos risks. This notification program involved use of the media and insertion of notices with about 30 million social security checks. In addition, a special mailing to all physicians in the United States was intended to increase knowledge of asbestos-related diseases. But beyond this, no provision was made for followup service for people responding to the announcements.

Another Government-sponsored approach was the Tyler (Texas) Asbestos Workers Program (TAWP). A grant to the University of Texas Health Center at Tyler was funded by the National Cancer Institute for the years 1974-79. TAWP was intended to be a model demonstration program of cancer prevention among a cohort of asbestos-exposed workers. (14). These workers were employed by the company that owns the Port Allegany factory, and they made the same product by using the same process. Production had begun 10 years earlier in Tyler, so that disease appeared there earlier than in Port Allegany.

The model program for the Tyler workers was well-conceived technically, and it included most of the elements needed for a medically useful effort. Unfortunately, emphasis soon shifted to aspects suitable for biomedical research, particularly the utility of sputum cytology examinations (15-19), rather than the utility of the model as a public health measure (14). The program became increasingly university-based, and community aspects were often neglected. After 2 years, smoking control, health education, and other proposed elements had not been implemented. Community health care providers were rarely involved. There have been reports that the term "asbestosis" was avoided, apparently to avoid legal problems. Gradually, the confidence of the workers in the program eroded. The 5-year grant from the National Cancer Institute was not renewed, and community support was not sufficient to allow TAWP to survive.

### **The Port Allegany Asbestos Health Program**

**Goals.** PAAHP's goal is to develop a permanent community health organization that will use the most advanced existing knowledge to mitigate the adverse health effects anticipated as a result of the use of amosite asbestos in a Port Allegany factory during the years 1964-72. Although PAAHP activities generate data useful for research, PAAHP is a service-oriented organization that provides preventive health services.

**Structure and governance.** PAAHP is a nonprofit corporation of the Commonwealth of Pennsylvania. Its funds are provided by the company, and it had early contributions from the union.

PAAHP is governed by a five-member advisory committee. The former plant manager and the union's international representative with responsibility for the Port Allegany local, who are cochairmen, have been adversaries for many years in negotiations over contracts and grievances. Their ability to "move to the same side of the table," as a local newspaper put it, has been a key to the development of PAAHP. Other members of the committee are the administrator of the Port Allegany Community Hospital, a local internist, and a local clergyman.

The Environmental Sciences Laboratory of the Department of Community medicine, Mount Sinai School of Medicine, New York City, has provided assistance to PAAHP for the development and implementation of its program. One of the authors (E.H.) regularly attends the meetings of the advisory committee by invitation, not as a member. More recently, technical assistance has also been provided by the Workers Institute for Safety and Health of Washington, D.C., established by the Industrial Union Department of the American Federation of Labor and Congress of Industrial Organizations.

**Population served.** All persons employed by the company in Port Allegany at any time between 1964 and 1972 are eligible for PAAHP services. (Manufacture of the asbestos product ended in 1972.) A computerized registry of these people has been compiled from company and union records. Of the 1,188 persons on the list, 108 are deceased at the time of writing. An additional 118 individuals have not yet been traced, although work on this continues. Ninety percent of those who have been traced still live within 25 miles of Port Allegany. A few have moved to distant States and are not expected to participate. The group's median age was 39 as of January 1, 1983, with a range of 29–83. All are white and 95 percent are men.

Everyone who lived in the households of the 1,188 workers when they were potentially exposed to asbestos is also eligible for PAAHP services. Enumeration of this group is not complete, but it is estimated that there will be approximately 3,000–4,000 such household contacts. In contrast to the worker cohort, there will be a broader age range, greater geographic dispersion, and more females than males.

**Scope of services.** PAAHP's major services are intensive medical surveillance, smoking cessation assistance, health education for participants concerning asbestos-related disease, and continuing education for area physicians concerning asbestos-related disease. Mineralogical evaluation of the factory is also performed to preclude continued exposure to persisting dust. Adjunct measures such as administration of influenza and Pneumovax vaccines are also provided. Although PAAHP does not handle workers' compensation claims, it does provide accurate information on the subject. Efforts are underway to provide counseling and psychosocial support when needed. PAAHP does not provide ordinary medical care or medical insurance.

**Organization of services.** PAAHP rents a 300-square-foot office on Main Street in Port Allegany. It is staffed by a full-time program coordinator who is a life-long resident of the town. She has professional training as a medical records librarian and has worked with many local health care providers and both nearby hospitals.

The frequency of medical surveillance and the specific tests performed are specified by protocols developed by the Environmental Sciences Laboratory. Participants are divided among five categories of risk, which are determined primarily by smoking history and the number of years elapsed since first exposure to asbestos. Examinations occur three times per year for those at greatest risk. Because few of PAAHP's participants had exposure to asbestos before 1964 (when the plant began to manufacture the asbestos product) and because few persons die of

asbestos-related disease until at least 20 years have elapsed since first exposure (1), fewer than 10 percent of participants require such frequent surveillance now. Eventually almost all will move into the three-times-per-year protocol, unless the protocols are modified on the basis of new data.

The program coordinator initiates surveillance examinations by contacting participants when called for by the protocols. Chest X-rays are taken at the Port Allegany Community Hospital. They are sent to the Environmental Sciences Laboratory for interpretation according to the "Guidelines for the Use of ILO International Classification of Radiographs of Pneumoconioses" (20). A report of this interpretation is sent to the PAAHP office.

Sputum samples are induced by the inhalation therapist at the hospital. Slides for cytology are prepared by the laboratory staff using the Saccomanno technique (21). For interpretation, the slides are mailed to Dr. Carolyn Watson of the Mount Sinai Department of Pathology. Her reports are sent to the PAAHP office, with a copy to one of the authors (E.H.)

All laboratory data are assembled into individual charts by the PAAHP office coordinator. The charts are kept in a locked cabinet; written policies specify that they may be released only to the participant or the physicians performing work for PAAHP. They may not be released to any other party, including the PAAHP advisory committee, the company, and the union, without written authorization by the participant.

When all scheduled tests are completed and results have been entered in the participant's PAAHP medical chart, he or she is seen by one of the local physicians working with PAAHP. So far, eight area physicians have worked with PAAHP. The physician inquires about relevant symptoms, performs a limited examination in accordance with the patient's protocol, and reviews the test results. Findings are recorded on forms developed by the Environmental Sciences Laboratory. Importantly, the physician educates and counsels participants about asbestos-related diseases. Finally, the physician reviews all findings and indicates whether there is a need to change the participant's protocol category. If a condition is found that requires further investigation or treatment, the participant is referred to his or her usual personal physician. This reflects PAAHP's policy not to disturb the patterns of ordinary medical care.

Although laboratory tests are performed at the Port Allegany Community Hospital, physicians have generally preferred to provide their part of the surveillance in their own offices with PAAHP participants scheduled among their usual patients. Physicians bill PAAHP for each office visit at a flat rate previously agreed upon. Similarly, the Port Allegany Community Hospital bills PAAHP for its services.

Assistance with smoking cessation is another important PAAHP service. Participants have been trained to be leaders of cessation groups by American Cancer Society and American Lung Association personnel. Several clinics have been held for smokers who want to quit, with the usual short-term success rate of 30–50 percent. Other methods of assistance are under development. Since 95 percent of those who stop smoking do so on their own without formal intervention (22), we are particularly interested in whether PAAHP'S health education program can augment the individual quitting process.

PAAHP's health education program concerning asbestos-related disease has several objectives. Participants need a balanced view of their predicament, neither underestimating nor overestimating it. To be able to help themselves, they need to be taught to recognize the early warning signs of treatable cancers, the value of medical surveillance, and the importance of smoking cessation and early treatment of chest infections. The educational objectives have been pursued in many ways—individual written reports of medical surveillance results with counseling included, personal counseling by examining physicians, monthly open meetings on Monday evenings in the PAAHP office, brochures mailed to each member of the cohort, coverage of PAAHP activities on local radio and television, talks before civic groups, and notices within the factory and in newspapers. In these efforts PAAHP has been assisted by the Workers Institute for Safety and Health, which has special experience in worker health education.

Continuing education for area physicians concerning asbestos-related disease has been provided whenever requested. At the invitation of local hospitals, E.H. has given numerous seminars at meetings of the staff of local hospitals. Reprints of important papers have been distributed. Four physicians who perform PAAHP surveillance examinations have come to the Environmental Sciences Laboratory in New York City for intensive review of asbestos-related disease and have received category 1 credits for the AMA Physician's Recognition Award.

Mineralogic evaluation of the factory in 1981 confirmed that airborne asbestos was no longer present.

**History.** PAAHP was founded in 1981, culminating more than a decade of discussion and several years of preliminary work among the union, the company, and the Environmental Sciences Laboratory. Early adversarial positions were gradually modified, and eventually Dr. Margaret Sloan, former chief of the Occupational Cancer Branch of the National Cancer Institute, described PAAHP as "the most remarkable example of union, management, and the community working together that I've ever seen" (23). PAAHP's history may

bear on the feasibility of using it as a model elsewhere.

In 1969, the medical director of the factory's parent corporation recommended that there be a medical program for the Port Allegany employees. The program that was established reflected the limited concept still followed in most company programs today—annual examinations of about 40 or 50 of the most heavily exposed workers and exhortations to stop smoking. No provisions were made at first for less heavily exposed workers, retirees, former employees, or household contacts. Examinations were not sufficiently frequent to improve cancer survival, and there was no attempt to integrate the services with primary care.

Because asbestos-related illness was not yet being observed and reported, the asbestos problem was not high among local concerns in Port Allegany in the 1960s. When the president of the local chapter of the union became an activist on the asbestos issue in the late 1960s, he was considered an alarmist and was voted out of office shortly thereafter. Several inspections by the Pennsylvania Bureau of Occupational Health in the late 1960s aroused limited interest. The company installed an entirely new ventilation system in the factory in 1969 in an attempt to suppress levels of airborne asbestos dust.

In 1971, Dr. William Johnson, Dr. Richard Lemen, and Dr. Joseph Wagoner of the National Institute for Occupational Safety and Health (NIOSH) met with company and union officials and recommended an expanded medical program. NIOSH performed one-time medical examinations of more than 300 employees that year. Few abnormalities were found then, reflecting the brief interval since the onset of exposure. The corporate medical director was apparently unresponsive to suggestions for a more comprehensive approach. Even in 1971 he maintained that 20 years or more of continuous, heavy asbestos exposure were required to produce asbestosis, an assertion contradicted by some of the earliest reports of asbestosis (24,25).

The Occupational Safety and Health Administration (OSHA) inspected the factory in 1971 and found airborne asbestos concentrations well above the legal standard in effect at that time. OSHA chose to classify these as "nonserious" violations, perhaps giving unfounded reassurance to those who were poorly informed concerning asbestos health effects.

In 1973, the president of the national union began to take an active, personal interest in the medical program for Port Allegany workers. His personal commitment and hard work have continued to the present. He pushed the company to expand the number of employees eligible for the program and to include former employees and retirees, understanding that the manifestations of occupational disease are often most pronounced among those no longer working. The union also began in 1974

to hold occasional meetings to increase the worker's awareness of the problem.

The company had had the opportunity of observing TAWP, the National Cancer Institute-funded plan at its Tyler plant, since 1974. In the same year, 445 Tyler employees filed a class action lawsuit for damages due to asbestos exposure. Among the defendants were the employee's union (a different union than the one representing the Port Allegany employees) and the company. The union was eventually dropped from the case, but the company agreed to a multimillion dollar out-of-court settlement in 1978. Although the possibility of similar lawsuits in Port Allegany may have been a factor in the thinking of both company and union officials, both parties agreed that PAAHP would be a health program that would deliver the best possible preventive services without regard to legal activities that might develop involving the company or union. Lawsuits have never been discussed at PAAHP meetings.

The early 1970s also marked the beginnings of public concern in Port Allegany. By then, news of the illness of Tyler workers was becoming known, particularly after a series of articles was published in *The New Yorker* in late 1973 (26). In 1974 the first Port Allegany worker received workers' compensation for asbestosis, and in the following year he died of respiratory failure. Also, in 1974, chest X-rays of six men in the company medical program were sufficiently worrisome that the X-rays were sent to a nationally known radiologist selected by the company. He reported that four had "simple pneumoconiosis."

By the mid-1970s, the company had expanded its medical program in Port Allegany to two or three times its original size. Only a few abnormalities were detected in the program at that time.

The president of the union requested the advice of the Environmental Sciences Laboratory in 1976. After review of the available information, a comprehensive approach was recommended; it is similar to what now exists. Company, union, and Environmental Sciences Laboratory representatives met in 1977, and a formal, written proposal for a comprehensive program was submitted to the company and the union shortly thereafter. The union quickly agreed to the proposal, but a year passed without a definite reply from the company.

Another meeting was held in 1978 at about the time HEW Secretary Joseph Califano began his public information campaign about asbestos health hazards. When there was still no progress, the president of the union, with urgency imparted by an ABC television special documentary he had just seen on health effects of asbestos, arranged to fly 38 Port Allegany workers to the New York area at union expense for thorough evaluations by the Environmental Sciences Laboratory.

On September 19, 1978, the report of the 38 examinations was released. It revealed that nearly all of these men had abnormalities consistent with asbestosis. This watershed event immediately affected the community, the workers, the union, and the company. It was the first unequivocal statement by independent professionals that the long-feared asbestos-related disease had arrived, not just in one or two isolated cases, but in nearly all who were examined. From that time on, the company too, with a new president, has vigorously supported the medical program.

In December, the president of the union and the new president of the company met with representatives from the Environmental Sciences Laboratory to suggest that a large-scale screening be conducted as soon as possible to define the problem better. At this time the company also agreed to make a small preplanning grant to the Department of Community Medicine, Mount Sinai School of Medicine, to study how a comprehensive program might best be developed.

In April 1979 the Environmental Sciences Laboratory mobilized 22 staff members and a van of equipment for a field survey in Port Allegany of workers and their spouses. Space was made available in the Port Allegany Community Hospital and the Masonic Hall, where examining booths were built by union men. Numerous residents provided volunteer help for the examinations. The police suspended parking regulations in the vicinity of the examination sites. The local newspapers supported the effort in their editorials and urged all those eligible to attend. The Rotary Club invited E.H. to give a luncheon address. A local minister praised the effort in his sermon that Sunday, and many other townspeople found ways to express their good will. As a result of broad community support, 355 workers and 111 of their spouses, or 80 percent of potential participants, took part in the examinations, including some who came from Florida, Illinois, and West Virginia.

The community was shocked, however, when a 24-year-old resident died of pleural mesothelioma in 1980. He had never worked with asbestos, but his father had, beginning in 1964, and was one of the 1,188 factory workers who became eligible for PAAHP services. The young man had remembered playing with his father's dust-laden respirator as a child.

Shortly thereafter, results of the large field survey confirmed the presence of abnormalities consistent with asbestosis in a considerable proportion of those examined. All parties moved quickly to form PAAHP.

## Conclusion

There has been a tendency in some quarters to categorize asbestos-related disease within one or another

narrow file as a labor-relations problem, a compensation problem, or, at best, a plant physician's problem. We suggest that it ought to be viewed as a public health problem. The sheer number of exposed people is enormous, and scarcely a community exists that does not have asbestos-exposed residents or potential asbestos exposure.

As a public health hazard, asbestos-related diseases will require public health measures, just as do waterborne diseases and tuberculosis. Individual medical care is unlikely to solve this problem. While the public health interventions available are not as effective as we would wish, there can be no doubt that application of existing knowledge can definitely prevent a significant number of premature deaths.

PAAHP is one approach to the problem of asbestos exposure. Its history illustrates the diversity of the forces and events leading to its formation, perhaps providing guidance for other communities. To be effective, it seems likely that programs dealing with asbestos-related disease must attract broad community support; the program in Tyler, Tex., illustrated that initial funding alone is not enough. Unless local physicians are an integral part of the program, unless workers are educated to understand the reasons for the program, unless they respect it enough to participate, and unless local support is sufficient to obtain long-term funding from appropriate sources, the effort cannot succeed. Although these conditions are not easy to achieve, PAAHP has demonstrated that such an approach is feasible.

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